



WORKBOOK

What Matters to Me

A Patient's Guide to Serious
Illness Conversations

NAME

DATE



the **conversation** project

This Workbook is designed to help people with a serious illness get ready to talk to their health care team (doctor, nurse, social worker, etc.) about what is most important to them – to make sure that they get the care they want.

This Workbook isn't about specific medical decisions. It's about telling your clinicians about your goals and preferences, and what matters most to you – so that together you can choose the kind of care that's right for you.

Take your time to complete the Workbook – you don't need to do it all in one sitting. If there are parts of the Workbook that you want to leave blank, that's okay. You don't have to fill out everything.

You might want to fill out the Workbook with a family member or friend. Or if you prefer, you can fill it out on your own, then share your answers and questions with a family member or friend. Be sure to bring the Workbook with you to your appointment so you can talk over your answers and questions with your health care team.

NOTE

If you are completing this document on a computer, first save it to your desktop with a name you can easily find again. Then open your saved document and type in your answers. (Otherwise, what you type will not be saved.)

Completing it on your computer will create a digital document that you can easily share with others.

My Health

➤ **What is your understanding of your current health situation?**

➤ **How much information about what might be ahead with your illness would you like from your health care team?**

About Me

MY GOOD DAYS • What does a good day look like for you?

Here are some things I like to do on a good day:

EXAMPLES

Have coffee with a friend • Sit in the garden • Go for a walk • Play the piano

MY HARD DAYS • What does a hard day look like for you?

These are the toughest things for me to deal with on a hard day:

EXAMPLES

Can't get out of bed • In a lot of discomfort • No appetite • Don't feel like talking to anyone

MY GOALS • What are your most important goals if your health situation worsens?

These are some things I would like to be able to do in the future:

EXAMPLES

Take my dog for a walk • Attend my son's wedding next September • Go to church services • Talk to my grandchildren when they come to visit

My Care

Everyone has their own preferences about the kind of care they do and don't want to receive. Use the scales below to think about what you want at this time.

Note: These scales represent a range of feelings; there are no right or wrong answers.

➤ **As a patient, I'd like to know...**

○ ○ ○ ○ ○

Only the basics about my condition and my treatment

All the details about my condition and my treatment

➤ **When there is a medical decision to be made, I would like...**

○ ○ ○ ○ ○

My health care team to do what they think is best

To have a say in every decision

➤ **What are your concerns about medical treatments?**

○ ○ ○ ○ ○

I worry that I won't get enough care

I worry that I'll get too much care

➤ **How much medical treatment are you willing to go through for the possibility of gaining more time?**

○ ○ ○ ○ ○

Nothing: I don't want to go through any more medical treatments

Everything: I want to try any medical treatments possible

➤ **If your health situation worsens, where do you want to be?**

○ ○ ○ ○ ○

I strongly prefer to be in a health care facility (hospital, rehab, or nursing facility)

I strongly prefer to be at home

➤ **When it comes to sharing information about my illness with others...**

○ ○ ○ ○ ○

I don't want those close to me to know all the details about my illness

I am comfortable with those close to me knowing all the details about my illness

➤ **MY FEARS AND WORRIES** • What are your biggest fears and worries about the future with your health?

These are the main things I worry about:

EXAMPLES

I don't want to become dependent • I don't want to be in pain • I don't want other people to see me in pain • I don't want to be a burden on my loved ones • I'm worried that I won't be able to get the care I want • I don't want to get stuck in a facility where no one will visit me

➤ **MY STRENGTH** • As you think about the future with your illness, what gives you strength?

These are my main sources of strength in difficult times:

EXAMPLES

My friends • My family • My faith • My garden • Myself ("I just do it")

➤ **MY ABILITIES** • What abilities are so critical to your life that you can't imagine living without them?

I want to keep going as long as I can...

EXAMPLES

As long as I can at least sit up on the bed and occasionally talk to my grandchildren • As long as I can eat ice cream and watch the football game on TV • As long as I can recognize my loved ones • As long as my heart is beating, even though I'm not conscious

If I become sicker, which matters more to me: Pursuing the possibility of a longer life, or pursuing the possibility of a good quality of life?

➤ **MY WISHES AND PREFERENCES** • What wishes and preferences do you have for your care?

If my health situation worsens, here's what I want to make sure DOES happen:

EXAMPLES

I want to stay as independent as possible • I want to get back home • I want my doctors to do absolutely everything they can to keep me alive • I want everybody to respect my wishes when I say I want to switch to comfort care only

And here's what I want to make sure DOES NOT happen:

EXAMPLES

I don't want to become a burden on my family • I don't want to be alone • I don't want to end up in the ICU on a lot of machines • I don't want to be in pain

What else do you want to make sure your family, friends, and clinicians know about you and your wishes and preferences for care if you get sicker?

My People

Are there key people (family, friends, others) who will be involved in your care going forward?

- **Who would you want to make medical decisions on your behalf if you're not able to?** This person is often called your health care proxy, agent, or surrogate.

Name, contact info, relationship to me

Yes No **I have talked with this person about what matters most to me.**

Yes No **I have filled out an official form naming this person as my health care proxy.**

Yes No **I have checked to make sure my health care team has a copy of the official proxy form.**

- **Who are the main people who will be involved in your care (family members, friends, faith leaders)?** For each person you list, be sure to include their phone number and relationship to you.

- **How much do they know about your wishes and preferences? What role do you want them to have in decision-making? When might you be able to talk to them about your wishes?**

My Health Care Team

Who are the key clinicians involved in your care?

- **My primary care provider**
Name Phone number

- **My social worker**
Name Phone number

- **My main specialist**
Name Phone number

- **Other**
Name Phone number

MY QUESTIONS

Here are some questions I would like to discuss with my health care team:

EXAMPLES

How will you work with me over the coming months? • What treatment options are available for me at this point – and what are the chances they'll work? • What can I expect if I decide I don't want more curative treatment? • If I get sicker, what can you do to help me stay comfortable? • What are the best-case and worst-case scenarios?

Next Steps

Now that you have completed your Workbook, be sure to talk it over with someone close to you – and then bring it with you to the appointment with your health care team to talk about the care you want.

- See The Conversation Project's free [How To Talk To Your Doctor](#) guide for useful advice about WHO to talk to, HOW to set up an appointment, and WHAT to say when you get there.
- Remember, the purpose of this conversation is not to make specific medical decisions. Instead, it's an opportunity for your health care team to listen and learn about what matters most to YOU, given your current health situation.
- The conversation can continue and change as your health changes. To get the best care possible, keep your health care team updated so they understand what's most important to you.

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